

The Role of Diabetes Health Care Professionals in Diabetes Discrimination Issues at Work and School

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When Jeff Kapche applied to be a police officer for the city of San Antonio, he was told “no” solely because he has type 1 diabetes. He sued the city. The case has been pending in federal court for the past 8 years. During that time, he has successfully held the position of sheriff in a neighboring county, experiencing no problems in his job because of his diabetes.¹

When Celeste Barselou wanted to start kindergarten at her neighborhood school, she was told “no.” The school district wanted to send her instead to a school more than an hour’s drive away where there was a full-time school nurse. No one would be able to help her with diabetes emergencies during the long bus trip each day.²

People with diabetes face discrimination at work, at school, and in many other places in their lives. While this certainly does not happen in every workplace or in every school, these problems are widespread, and they are serious. The American Diabetes Association (ADA) is committed to ending this discrimination through its legal advocacy program.

This article provides background on the legal landscape of diabetes discrimination, describes ADA’s efforts to combat discrimination, and explains the essential role that dia-

betes health care professionals can play in ending discrimination against people with diabetes. It focuses on discrimination in the workplace and at school, but discrimination can and does exist in many other places and situations, ranging from obtaining private driver’s licenses to securing proper medical treatment in correctional facilities.

Why Discrimination Should Matter to Diabetes Health Care Professionals

Diabetes health care professionals work hard to help their patients understand the importance of good diabetes management and to help them to make the lifestyle changes that make good management possible. However, as diabetes professionals are acutely aware, the ability of people with diabetes to manage their disease depends on a variety of societal factors. Sometimes, as with schoolchildren, people with diabetes cannot self-manage their diabetes unless others, in this case school officials, permit them to do so. Adults with diabetes who face discrimination in the workplace are limited in their ability to provide economically for themselves and their families. Thus, it is useful to think of discrimination against people with diabetes both in terms of fairness issues and as a matter of facilitating good diabetes management.

Diabetes health care professionals may find themselves involved in discrimination issues in the regular course of patient care. Sometimes, patients may describe a problem at work or school and seek help. Other times, patients may resist a course of treatment in order to avoid potential problems at work. For example, truck drivers who begin insulin therapy may

very well lose their job. Health care professionals should be alert to the impact decisions at work or school may have on patients’ willingness—as well as ability—to abide by a particular course of diabetes management.

In addition, any time a health care professional fills in a form for a school, employer, or licensing board, the form is used by individuals who then decide whether to treat a person with diabetes fairly. These forms may contain legal terms, words such as “disability” or “qualified,” that can have a significant impact on how a person with diabetes is treated. Thus, it is important for health care professionals to understand this legal terminology and how these forms are being used.

Finally, much of the discrimination people with diabetes face is a result of decision makers not understanding diabetes and how it is successfully managed. Diabetes professionals come into contact with a wide variety of people whom they educate about diabetes. Through this education process, they dispel myths and stereotypes about diabetes and thus prevent discrimination from occurring.

When legal action is necessary, diabetes health care professionals are needed to consult with lawyers who are trying to understand the medical issues involved in a given case and to appear as expert witnesses to explain diabetes to the judge or jury. The laws protecting people with diabetes from discrimination require courts to fully understand how diabetes affects the individual involved. Simply put, no lawsuit involving discrimination based on diabetes can be won without assistance from diabetes health care professionals.

Discrimination in the Workplace

ADA has two goals for achieving fairness for people in the workplace:

- No one with diabetes is denied a job for which he or she is qualified because that person has diabetes.³
- Each person with diabetes is afforded the reasonable accommodations necessary to protect his or her health on the job.

The first goal acknowledges that not everyone with diabetes is qualified to do every job. Some people, because of the way the disease affects them individually, are unable to perform some jobs. For example, someone with severe hypoglycemia or hypoglycemic unawareness would not be qualified for a job involving commercial driving or law enforcement. In addition, not everyone has the training or skills necessary for every position.

This goal, however, recognizes that people should be assessed individually with regard to how diabetes affects them. Accordingly, there should not be any blanket bans that eliminate a person from a job solely because of his or her status as a person with diabetes or a person who takes insulin, as was the case with Mr. Kapche, the aspiring police officer introduced at the beginning of this article.

The second goal—obtaining reasonable accommodations—involves employers making usually minor changes to ordinary routines that can facilitate a person with diabetes being able to accomplish the job in question. This might mean allowing the employee a break of a couple of minutes to check and treat his or her blood glucose level. It might mean allowing someone with severe neuropathy to take a shortcut through the building that other employees do not have access to, or it could mean providing a larger computer screen for a person with retinopathy. Sometimes, accommodations might be more complicated, such as avoiding shift work for employees with diabetes who have difficulty managing their disease when working under varying schedules.

Employment civil rights laws

Several important civil rights laws provide protection against discrimination in the workplace. The Americans with

Disabilities Act, the Rehabilitation Act of 1973, and the Congressional Accountability Act are federal laws that protect workers with disabilities. In addition, almost all states have their own anti-discrimination laws. The federal Family and Medical Leave Act, while not a civil rights law, is important for people with diabetes because it allows individuals to take up to 12 weeks of unpaid leave per year to deal with their own or a family member's serious medical condition.⁴

Although these laws are crucial tools for workers with diabetes, they also present a number of hurdles. To prevail, workers with diabetes must establish that they are qualified people with a disability and that they were discriminated against because of diabetes. In meeting these legal requirements, people with diabetes often face a double-edged sword.

Jeff Kapche is a good example. The city of San Antonio admitted that it would not hire him because of his diabetes. Specifically, the city feared he would experience debilitating hypoglycemia on the job even though he had no history of severe hypoglycemia and had an otherwise excellent health record. Yet, when sued, the city claimed that it could not be held accountable under the Americans with Disabilities Act because Mr. Kapche does not have a disability as defined under that law. Thus, Mr. Kapche first had to prove that he either had a disability, had a record of a disability, or was regarded as having a disability. Then, he had to establish that he could safely perform the job of a police officer.

The term “disability” is difficult for many people with diabetes—and their health care providers—to accept. Diabetes professionals spend a good deal of time helping their patients develop a “can-do” attitude towards diabetes management. The concept of disability may seem antithetical to that. The reality of the legal world, however, is that if a person is not found to be covered by disability rights laws, then it is perfectly legal for an employer to refuse to hire that person simply because he or she has diabetes. Thus, “disability” is a legal term that must be understood and accepted in this context. A diabetes professional can help a court under-

stand that the individual in question merits protection under civil rights laws by explaining the complex regimen the worker follows to keep blood glucose levels in balance and the short- and long-term consequences of failing to do so. The health care professional can then help the court understand how this worker can also be quite capable of performing the job in question by explaining the many available tools for diabetes management and how the worker can employ them to successfully and safely perform the job at issue.

Discrimination at Schools and Day Care Centers

ADA has two goals for achieving fairness at schools and day care centers:

- Students with diabetes are medically safe at school and at day care facilities.
- Students with diabetes have the same access to educational opportunities as do other children.

The major barriers students with diabetes face are: 1) a lack of timely access to the tools for diabetes management (blood glucose monitoring equipment, insulin, food/liquids, glucagon); and 2) a lack of school personnel who are knowledgeable about diabetes and able to assist when needed during both school hours and extracurricular activities.⁵ These barriers result in students not receiving glucagon in emergencies, students missing significant classroom instruction in order to check blood glucose levels, and students being told that they cannot participate in field trips or—worse yet—that they cannot attend their neighborhood schools at all.

ADA's advocacy efforts are geared toward educating school decision makers that, for health and safety reasons as well as for educational reasons, it is crucial to facilitate good diabetes management at school. The second part of ADA's message is that such management can be accomplished easily. An adequate number of school personnel should be trained in the necessary diabetes procedures (e.g., blood glucose monitoring, insulin and glucagon administration) and in the appropriate response to high and low blood glucose levels to

ensure that at least one adult is present to perform these procedures in a timely manner when a student with diabetes is at school, on field trips, and participating in extracurricular activities or other school-sponsored events. The diabetes health care profession supports the notion that these school personnel need not always be health care professionals, such as school nurses, but can also be teachers, administrators, or support personnel who have received training in diabetes care in school.⁶

Education laws

Three important federal laws provide protection to students with diabetes. Section 504 of the Rehabilitation Act of 1973 ("Section 504") and the Americans with Disabilities Act are civil rights laws geared at assuring equal access for students with disabilities. The Individuals with Disabilities in Education Act (IDEA) provides special education for students whose diabetes negatively affects their ability to learn, such as students who experience recurring high and low blood glucose levels at school that make it difficult to concentrate or who, because of complications, must miss large amounts of classroom instruction.

In addition, the Family and Medical Leave Act allows parents to take time from work to deal with the medical needs of their children. This is not to imply that parents should be required to provide diabetes care at school, but rather that such leave could be used when a child must miss school because of illness or appointments with health care providers.

These laws are useful not just when problems occur, but also as a means of preventing difficulties by making sure that the people and tools for good diabetes management are in place and that all involved parties know their responsibilities. This is best done by putting diabetes management information in writing at the beginning of each school year or as soon after a child is diagnosed as possible.

First, each student's diabetes health care providers should provide information regarding blood glucose monitoring, insulin, meals and snacks, treatment of hypoglycemia and hyper-

glycemia, and exercise and sports. This is done in a document that is sometimes called a "Diabetes Health Care Plan" but may have a different title in different schools. ADA has a sample plan available at www.diabetes.org/main/community/advocacy/504plan.jsp.

In addition to a Diabetes Health Care Plan, it is useful to have an education plan developed jointly by each child's family and school officials that explains how these medical needs are to be implemented at school. The education plan should cover areas such as (but not limited to) access to food and water, where blood glucose monitoring occurs, whether help is needed with administration of medication, who is trained to provide assistance for routine care or in case of emergency, and how the plan will be implemented during extracurricular activities and on field trips.

The education plan can be developed pursuant to Section 504, in which case it is usually called a "504 Plan," or pursuant to IDEA, in which case it is referred to as an "Individualized Education Program" or "IEP." ADA has a sample 504 Plan at www.diabetes.org/main/community/advocacy/504plan.jsp. The plan can also be done informally, that is, not pursuant to any law, but will confer fewer rights on the parents if done in this manner. Because families may not be aware of these laws and the need to have signed documentation from their child's health care providers, diabetes care providers can greatly assist their patients who attend school by asking if these plans are in place before the beginning of each school year.

ADA's Response to Discrimination

ADA's response to discrimination, whether at work, at school, or elsewhere, involves the same four-step process: **Educate, Negotiate, Litigate, Legislate**. The goal is to resolve the problem at the earliest step possible, while being prepared to move on to the other steps as necessary.

In all areas of legal advocacy, ADA's work is firmly rooted in the science of diabetes and the authority of ADA as a scientific health care organization. ADA has developed peer-reviewed position statements in the area of schools, employment, and

correctional facilities that guide legal advocacy efforts in those areas.^{3,6,7}

Educate

Most of the discrimination people with diabetes experience is the result of ignorance about diabetes and especially about diabetes management today. In addition, people with diabetes and those who make decisions involving their rights often do not understand the legal rights of people with diabetes.

ADA works hard to educate decision makers about the capabilities and needs of students and workers with diabetes. In the school area, ADA proposed that federal agencies and diabetes and education organizations join forces to develop materials that represent a broad consensus on the best approach to management of diabetes at school. The result is the National Diabetes Education Program's Diabetes in Schools Initiative, a collaborative effort of the National Institutes of Health, Centers for Disease Control and Prevention, U.S. Department of Education, American Diabetes Association, American Association of Diabetes Educators, Juvenile Diabetes Research Foundation, and many others. The initiative is currently in the process of completing a manual to provide guidance to school personnel across the country. This manual will be available during the 2002–2003 school year and will be announced at www.ndep.nih.gov. As a supplement, ADA is developing training materials for school employees who will actually perform diabetes care tasks at school. ADA also partnered with the American School Health Association on its premiere issue of *Health in Action*, which is devoted to the management of diabetes in school and to the prevention of type 2 diabetes.⁸ Similar partnerships occur in the employment area. For example, ADA partnered with Cornell University to create materials to explain the legal rights of workers with diabetes to employers.⁹

ADA has created comprehensive packets of materials to help people with diabetes understand their legal rights at work and at school. These packets are available by calling 800-DIABETES, and many of the materials can be accessed online at

www.diabetes.org/main/community/advocacy/discrim.jsp.

Diabetes health care professionals play a crucial role in this education process. For example, diabetes professionals are needed to train school personnel and employers about diabetes management. They are often asked to evaluate their patients and let employers know what a specific employee is capable of doing or what a given student needs to be safe and able to participate at school. In addition, ADA encourages health care providers to inform their patients about their legal rights through pamphlets such as *Your Job & Your Rights* (available by calling 800-DIABETES or at www.diabetes.org/main/community/advocacy/workplace_discrim.jsp) and *Your School & Your Rights* (available by calling 800-DIABETES or at www.diabetes.org/schools).

For more information, see “What Should You Do If You Think a Patient Is Being Discriminated Against Because of Diabetes?” on this page.

Negotiate

When education alone does not work, negotiation requires knowing what carrots or sticks to use to achieve fairness in the workplace or at school.

Negotiation tools include having a lawyer explain to the decision maker the legal rights of people with diabetes, having a health care professional explain the consequences of not facilitating good diabetes management, seeking help from elected officials and government agencies, and exerting pressure through the media. ADA has a legal advocate on staff to talk to individuals facing discrimination in order to help them understand the legal landscape and possible negotiation tools. ADA’s Call Center, 800-DIABETES, puts individuals with specific discrimination problems in contact with the legal advocate.

Litigate

ADA serves as both a scientific and a legal resource to lawyers pursuing litigation, whether in the form of an administrative complaint or a lawsuit in state or federal court. ADA’s scientific materials provide authoritative resources to educate courts about diabetes. Through its legal advocacy program, ADA develops key legal argu-

ments for diabetes discrimination cases. Putting these two activities together, ADA then provides guidance to lawyers around the country on how to best apply this legal and medical expertise to individual situations.

ADA has developed an Advocacy Attorney Network made up of lawyers around the country who have expressed an interest in working on diabetes discrimination cases, usually without cost to the individual seeking help. In the most important cases, ADA becomes directly involved either as a party to the litigation itself or as an amicus curiae (friend of the court) writing legal briefs to explain the science of diabetes and ADA’s legal position. ADA has been involved in numerous victories in this area, ranging from settlement agreements in school and day care discrimination cases to victories in federal courts of appeal on employment issues.^{10–12}

What Should You Do If You Think a Patient Is Being Discriminated Against Because of Diabetes?

1. Find out whether your patient has tried to educate the person who is acting unfairly about diabetes and current methods of diabetes management. Provide written materials and, if possible, offer to talk to the decision makers about diabetes management.
2. Provide the patient with a copy of ADA’s pamphlet *Your School & Your Rights* or *Your Job & Your Rights*. These pamphlets can be obtained by calling 800-DIABETES.
3. Tell your patient to call ADA at 800-DIABETES and ask for a copy of the education or employment discrimination packet or other materials if the discrimination involves another area. Explain that he or she will be able to speak directly with ADA’s legal advocate about specific discrimination concerns.
4. Follow up and make sure that the difficulties your patient is facing are not compromising his or her ability to effectively manage diabetes.

Diabetes health care professionals play a crucial role when discrimination matters reach the litigation stage. They are needed to help lawyers assess the viability of potential claims. Moreover, no plaintiff with diabetes will be able to prevail in litigation without medical evidence supplied by his or her health care providers and—better yet—additional evidence supplied by an outside health care expert.

Legislate

Sometimes, existing laws do not provide the protection from discrimination that people with diabetes need, and a legislative change is necessary. The legislative process can be used in a variety of ways. For example, U.S. Department of Transportation (DOT) regulations currently prohibit anyone who uses insulin from driving a commercial motor vehicle in interstate commerce. ADA successfully lobbied Congress to require DOT to reevaluate this regulation. As a result, there is now a proposed rule that would provide for individual assessment of each potential commercial driver.

The rule calls for careful screening, stringent guidelines for drivers to use when on the road, and an aggressive monitoring program to ensure safety. Unfortunately, the proposal also requires an individual to have driven a commercial vehicle while using insulin for the 3 years immediately prior to applying to drive commercially in interstate commerce—something that is almost impossible to do and thus would block most capable drivers from obtaining licenses. ADA is now working to change this provision, while making sure that individual assessment replaces blanket prohibition.

In the school area, ADA found that although federal laws provide protections for students with diabetes, these laws are difficult to enforce in each and every recalcitrant school district. As a result, ADA has developed model state legislation that sets out the basics of what students with diabetes need, focusing on having trained staff who can help younger students with diabetes care tasks and help all students with diabetes in case of medical emergency. So far, general school legislation has been passed in Virginia and Washington, and specific legislation

concerning glucagon has been passed in Wisconsin and Tennessee.

As of August 2002, efforts are either underway or being considered seriously in a number of other states including Arizona, California, New York, North Carolina, Pennsylvania, Minnesota, Rhode Island, and South Carolina. Further information about legislative initiatives can be obtained by calling 703-253-4362 or sending an e-mail inquiry to LegalAdvocate@diabetes.org.

Your Role in Legal Advocacy: The ADA Health Care Professional Legal Advocacy Network

The key to successfully fighting discrimination is effectively explaining diabetes to decision makers, be they bosses, school principals, judges, or juries, who determine how diabetes management is implemented within their realm of authority. It is impossible to do this without the active support of diabetes professionals at every step. Sometimes, health care professionals are involved in legal advocacy through the normal course of filling out required forms that explain what their patients can do and what they need to do it. In other instances, the advocacy element is more overt, such as when health care providers are asked to provide training to institutions, to evaluate an individual with diabetes with regard to specific legal claims, to provide expert testimony in lawsuits, or to testify about the medical need for legislation.

In response to the multifaceted role of health care professionals in securing the legal rights of people with diabetes, ADA has created the ADA

Health Care Professionals Legal Advocacy Network. The newly formed network is composed of diabetes health care professionals around the country who have agreed to volunteer in diabetes discrimination matters. Joining the network does not obligate a member to become involved in any specific issue. Rather, when an issue arises in a member's geographical area and area of practice, that member may be contacted to see if he or she is interested and available to participate. For more information about the network, including information about joining, call 703-253-4362 or e-mail an inquiry to LegalAdvocate@diabetes.org.

Discrimination against people with diabetes remains a serious problem, but legal advocacy offers diabetes health care professionals many exciting—and worthwhile—opportunities to improve the lives of people with diabetes.

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